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TITLE

Factors influencing the implementation of cognitive and behavioural screening in Motor Neurone Disease.

ABSTRACT (100-150 words)

Changes in cognition and behaviour occur in approximately 50% of people with Amyotrophic Lateral Sclerosis (ALS), the most common form of Motor Neurone Disease (MND). The aim of this study was to explore current factors influencing the implementation of cognitive and behavioural screening in MND care in the UK. Semi-structured interviews with healthcare professionals working in a range of settings were conducted and data were analysed thematically. In most of the settings included, a pathway to screening and neuropsychological intervention had not yet been established. Factors identified as barriers included: limited number of staff trained to administer screen, limited time available during outpatient clinic hours, and limited or no links with neuropsychological services. Screening was implemented routinely in one setting where there was support from a clinical neuropsychologist working within the MDT. Support from neuropsychological services was suggested to be necessary for interpretation of screening results and advice on intervention.

KEYWORDS

Motor Neurone Disease; Amyotrophic Lateral Sclerosis; cognition; behaviour; screening

KEY POINTS

1. Cognitive and behavioural screening is an important component in the assessment and management of people with ALS/MND and is recommended in National Institute for Health and Care Excellence guidelines.
2. Although healthcare professionals are aware of screening tools and have a positive attitude to screening, it is not currently implemented routinely in all settings.

3. Factors influencing implementation of screening include: availability of staff trained to administer a screen; availability of time for cognitive/behavioural screening; extent of support from neuropsychological/psychological services with interpretation of screen and intervention.
4. Developing links with neuropsychological/psychological services may be key to establishing effective, routine screening.

BACKGROUND

Motor Neurone Disease (MND) is a rapid neurodegenerative syndrome which causes progressive physical disability due to the degeneration of the motor neurones. Amyotrophic Lateral Sclerosis is the most common form and is characterised by involvement of both upper and lower motor neurones. Around 15% of patients diagnosed with ALS will also meet criteria for a diagnosis of frontotemporal dementia (FTD), while approximately a further 35% will experience some cognitive and behavioural changes (Goldstein and Abrahams 2013). These changes add further complexity to the management of the disease. The cognitive domains commonly reported to be affected include language and executive functions, while the most prominent behavioural symptom is reported to be apathy. These changes have the potential to increase caregiver burden (Lillo et al. 2012; Andrews et al. 2017), affect patient adherence to life-prolonging interventions (Olney et al. 2005; Martin et al. 2014; Govaarts et al. 2016) and clinical decision-making (Oliver and Turner 2010).

A previous study published in the *British Journal of Neuroscience Nursing* reported clinicians' attitudes to implementing cognitive and behavioural screening in MND (Crockford, Stockton and Abrahams 2017). The findings were relevant to Scotland and the data was collected in early 2015. A number of new developments in MND care in the UK have occurred since that time which may have influenced clinician's attitudes and practices related to cognitive and behavioural screening.

Firstly, the Edinburgh Cognitive and Behavioural ALS Screen (ECAS) originally published in 2014 has gained further popularity as a tool of choice for assessing patients with MND. The ECAS was designed for patients with motor dysfunction and provides a brief assessment of the cognitive functions known to be affected in MND, along with a screen for behavioural symptoms based on the latest diagnostic criteria for behavioural variant FTD (<https://ecas.psy.ed.ac.uk/>). The ECAS has now been validated against extensive neuropsychology and compared with other screening batteries in the UK (Niven et al. 2015) and in Europe (Lulé et al. 2014; Poletti et al. 2016; Mora et al. 2017; Pinto-Grau et al. 2017). Secondly, updated guidelines from the National Institute for Health and Care Excellence (NICE) published in 2016 incorporated recommendations for cognitive and behavioural assessment in patients with MND. These guidelines promote the need for clinicians to consider patients' cognitive and behavioural status when communicating with patients, when considering clinical interventions and when guiding patients through end-of-life planning. The guidelines state that members of the multidisciplinary team should assess and manage cognition and behaviour and the team should have established links with psychology/neuropsychology services (NICE, 2016). Thirdly, following the publication of the NICE guidelines, increased support from ALS charities has been given for educational activity for health professionals aimed at raising awareness of cognitive and behavioural change in MND.

This study aims to explore clinicians' attitudes and practices related to cognitive and behavioural screening in MND. This study expands on previous research which focused on Scotland (Crockford et al. 2017) to explore attitudes and practices in England and Wales in the period after significant efforts to raise awareness of cognitive and behavioural change in MND were initiated.

METHODOLOGY

Recruitment

Participants were healthcare professionals in working as part of a multidisciplinary team providing care to people living with MND. They were recruited from five NHS health trusts in England and Wales. We used purposive, heterogeneous sampling in order to achieve maximum variation in the type of care contexts included. We recruited health professionals from five healthcare teams, labelled A-D in Table 1.

Procedure

Data were collected using individual semi-structured interviews, conducted by telephone, between February 2017 and April 2017. Interviews lasted approximately 30 minutes. A topic guide was used and questions were derived from literature review and clinical insight into the day-to-day operations of an MND care team. Interviews were audio-recorded and then transcribed with the participants' consent.

This study was deemed to be service evaluation and approved by the Research & Development departments in each health trust. A favourable ethical opinion was given by the Psychology Research Ethics Committee of the University of Edinburgh.

Thematic analysis was conducted using the Framework Analysis method (Ritchie and Spencer 1994). The Framework Matrices function on NVIVO 10 (QSR International Pte Ltd, Doncaster, Victoria, Australia) aided in the organisation of summarised data into matrix cells and enabled the retention of an electronic link between these summaries and the data in the original transcripts.

RESULTS

Participants

Participants included a neurologist, two speech and language therapists, a specialist nurse and a consultant in palliative medicine. Participants had a mean of 17 years' professional experience working in MND care (range 5-28 years).

Attitudes and practices

Participants had a positive attitude towards screening, suggesting that it allowed the identification of cognitive and behavioural changes that could otherwise go unrecognised in patients. Screening was also reported to inform how care is tailored to patients' individual needs, particularly in regard to decisions on medical intervention (e.g. gastrostomy) and end-of-life decisions (e.g. power of attorney), as well as helping care teams to support patients' families. Although all respondents had positive attitudes towards screening, it had not been implemented across all settings. Table 1 describes the current local pathways in place in each context, as reported by each participant.

Barriers and facilitators to screening

1. Knowledge of cognitive and behaviour change in MND

Each participant initially became aware that cognition and behaviour may be affected in MND through their clinical work and, subsequently, became better informed about the nature and extent of these aspects of the disease by attending study days where cognition and behaviour was discussed and/or reading relevant scientific literature. All participants reported that some of their colleagues had also attended study days.

2. Implementation of a clinical pathway to screening

Participants mentioned the need to consider the local context when developing a pathway to screening. They were in agreement that administering a screen was within the capabilities of a health specialist and that, ideally, they would receive supervision from a clinical neuropsychologist. Health specialists in the multidisciplinary team (MDT) identified as suitable to undertake screening included: occupational therapists, speciality doctors, nurse specialists, MND Care Coordinators, speech and language therapists, clinical/neuropsychologists and assistant psychologists.

Establishing routine screening for all patients was suggested to normalise the experience, thereby making it less "scary" for patients.

Nurse Specialist- Team C: “we feel that they’re more receptive or open to doing it because, one, they recognise or realise that we’re doing it on everybody so they’re not being separated out for any reason, two, because if we do find something early, they’re recognising that we can put something into place to help them overcome some of the issues that they may be faced with”

The majority of respondents worked within MDTs where at least some members of the team had access to their patients in a range of contexts (e.g. outpatient clinic/patient’s home/hospital ward). A care team’s flexibility to implement the screen in a range of suitable contexts was suggested to be key to successfully establishing routine screening as MND clinics are often busy and time is a limited resource.

Nurse Specialist- Team C: “...it might be that we’re seeing them for the first time in hospice or in a nursing home...it doesn’t particularly matter where the patient is as long as the patient is comfortable and it’s in a place where...we’re going to get the same result...”

Another respondent suggested that, where contact with patients occurred only in the context of a busy MDT outpatient clinic it may be necessary to have a psychologist working as part of the clinic team and available to administer screening.

SALT- Team B: “A clinical swallowing assessment will take maybe half an hour...I’m very aware that they then have to go on for respiratory tests and physio and if I spend any more time with them then they won’t go through their pathway and they’ll be too fatigued...to be able to say to people “if you could stay for lunch then in the afternoon you could have this assessment [with the psychologist]”.

3. Access to appropriate screening tools

Participants were aware of cognitive and behavioural screening tools. The interviewer prompted each respondent to discuss the ECAS, in particular. The most widely mentioned advantage of the ECAS was that it had been specifically designed and validated for the MND population and,

therefore, included tasks and questions related to the specific areas of cognition and behaviour that can be affected.

The ECAS was also described as a short and straightforward assessment which could be administered by a range of health professionals in a multidisciplinary team. These features were suggested to help health professionals incorporate the screen into their practice and to limit the potential for patient fatigue when completing the screen.

Nurse Specialist- Team C: “MND patients can do it. They can really do it, really easily and simply. The instructions to do it were really simple and straightforward and, actually, convincing the rest of the team that this was the way forward didn’t take that long”.

4. Availability of time & staff

While the majority of participants deemed recording “baseline” measurements of cognitive function and behavioural anomalies to be important, in contexts where there was a lack of time or availability of trained health professionals to administer a screen there was a tendency for this to be viewed as less important than other clinical assessments.

SALT- Team B: “if I’ve got five patients backed up to see that morning then I wouldn’t be able to do the ECAS because the priority would be doing the swallowing assessment which is more life-threatening”.

Use of cognitive and behavioural screening tools requires the administrator and patient to be fluent in same language or for an interpreter. One participant based in a clinic in an urban area reported this to be a barrier to screening some patients as the use of interpreters was viewed as impractical.

5. Access to neuropsychological services

There was a clear disparity between the different care contexts in which participants worked in the current level of engagement with neuropsychological services (see Table 1). Nevertheless, all respondents described the valued contribution that such links could bring. This included: help with

the assessment of complex cases; interpretation of cognitive/behavioural assessments carried out by other health specialist in the MDT; and advice on intervention.

Neurologist- Team E: "It would be useful to have somebody in the background to help, not only with assessments but...to know and give us advice on what to do with that information...how it might translate into clinical practice. That would be ideal."

One respondent expressed concern that without an established link with neuropsychology, the MDT were "left with a piece of information [they] can do nothing with" (Palliative Care consultant- Team D).

DISCUSSION

All health professionals who participated were aware that cognition and behaviour can be affected in MND and viewed cognitive and behavioural screening as being beneficial for managing patient care. They showed awareness of cognitive and behavioural screening tools and a majority had experience in using the Edinburgh Cognitive and Behavioural ALS Screen (ECAS).

Despite the good level of knowledge and positive attitude to screening among the healthcare professionals interviewed, local pathways to screening and neuropsychological intervention had, for the majority, not been fully implemented. In particular, the widespread lack of links or communication with neuropsychological services, whether due to real or perceived paucity of these services, was notable. In the one location where screening was conducted routinely, there was support from a neuropsychologist. In addition, several staff at that location were trained to administer the screen and had the flexibility to do so in a range of locations, therefore avoiding the necessity of fitting the screen into the schedule of a busy MND outpatient clinic.

Some health professionals reported that they would usually only screen patients when cognitive and behavioural symptoms had already been noted informally. As suggested by Crockford et al. (2017), this may be because these health professionals believe their clinical judgement of cognitive and

behavioural impairment to be reliable, but this is not supported by evidence showing poor accuracy of physicians in this regard (Mitchell et al. 2011). Health professionals may also be relying on their clinical judgement because of the perceived barriers to screening including: lack of staff time to undertake screening; other assessments being viewed as of higher priority; and, lack of neuropsychological support to help with interpretation and intervention.

In contrast with the current study, a significant barrier to screening patients noted by Crockford et al. (2017) was the lack of knowledge and training available to MND care staff on the nature of cognitive and behavioural changes in MND, the assessment of those changes, and how to take account of a patient's cognitive status when managing their care. This was not reported in the present study. It seems that the publication of the NICE guidelines (2016) and efforts made by various individuals and organisations to raise awareness and hold educational seminars for health professionals may have had an impact as the health professionals interviewed for this study all showed a good level of awareness and did not indicate a lack of knowledge or educational opportunities as a barrier to implementing screening.

Limitations

This was a small-scale study which aimed to extend the reach of findings reported previously in a study conducted in Scotland. Although we successfully included participants from a range of different types of service providing care to people with MND, only one participant from each setting was interviewed. Further research taking account of the views of different health professionals working in the same setting, would be required to gain an in-depth understanding of the systemic barriers to implementing screening. The views of clinical neuropsychologists would be of particular interest as this profession was not represented in the current sample.

CONCLUSION

Health professionals included in this study recognised the importance of screening patients for cognitive and behavioural change and, furthermore, showed good knowledge and awareness of these changes. Screening appears to be working well for those in which a local pathway has been implemented from assessment to neuropsychological intervention and where a range of staff are trained to screen patients, doing so in and outside of the clinic setting. However, for the majority, there was not a local pathway operating and MND care services were not accessing neuropsychological support. Securing support from local neuropsychological services may incentivise multidisciplinary teams to implement screening with supervision from a neuropsychologist or enable direct referrals.

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